

# Community Rehabilitation in Neurology



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## **Background to community neurological rehabilitation**

Why did we want to write this book? There are now many textbooks on rehabilitation, including an increasing number specifically about neurological rehabilitation. However, most of these texts are written from the standpoint of a traditional hospital-based medical speciality. Many, understandably, deal with diseases and symptom management with very little attention paid to the broader concepts of disability and community participation. Many disabled people either never enter hospital or spend only a small proportion of their lives within a hospital rehabilitation unit. Thus, it is ironic that modern rehabilitation practice, at least in the Western world, has a hospital focus. There is a clear need for coordinated rehabilitation to be provided in the home, or at least in the local community. This is a significant gap in health-service provision.

We are not aware of any major review of the literature on community rehabilitation and thus we thought it was an opportune moment to write this book. The expertise of the lead authors is in the field of neurological rehabilitation and so we have generally restricted our comments and critiques to this arena. Our primary aim is to review the need behind the provision of community rehabilitation and address the evidence for the efficacy of such community interventions. We hope this will not only stimulate clinical developments in this field but also encourage further research so that the evidence base may become more robust than at present. We hope that we have succeeded in these aims.

Neurological rehabilitation practice in the developed world (the North in modern parlance) has tended to be hospital focused and has concentrated on assisting disabled people in the postacute phase of their disability. This is the phase that follows in the weeks and months after an acute disabling event, particularly stroke and traumatic brain injury. There has been scant

attention to the needs of disabled people after this phase is over and after they have been discharged back home. Modern neurological rehabilitation has often failed to deal with the needs of individuals who never come to the attention of an acute rehabilitation unit, such as those people with cerebral palsy or multiple sclerosis. These people mainly live in the community and only come into contact with rehabilitation practice at the time of a relapse or the appearance of a complication. Many such complications are unnecessary and avoidable if the individual had access to an expert multidisciplinary rehabilitation team throughout their life. It is a pity that rehabilitation has largely become a hospital based speciality as by so doing the longer-term needs of people with neurological disabilities can be overlooked. It is also a pity that community rehabilitation has been perceived as an area into which the health professional should not readily stray. It is certainly true that when disabled people are living at home much of their restriction is not due to their own particular disabilities but to the problems of society. Environmental and attitudinal barriers undoubtedly restrict active participation by disabled people in the local community, in employment, in leisure pursuits and even within their own families. Such societal issues go beyond the expertise of the health professional but surely the clinician has an important role to play in a community setting.

There are indications that health systems are beginning to recognize the longer-term health and rehabilitation needs of disabled people who are living at home. In many countries government resources are beginning to be directed away from acute, and expensive, hospitals towards healthcare delivered within the community. There is more emphasis on the general practitioner and the primary care team. There is also increasing emphasis on initiatives that help support the disabled person within their own home and prevent unnecessary admission to hospital. There are other schemes that facilitate discharge from hospital and support the disabled person after discharge. There are increasing numbers of health professionals who have a remit, either full-time or part-time, to work in the community. We are beginning to see the expert rehabilitation nurse or therapist venturing away from the hospital doors. This is a trend to be encouraged. It is certainly a trend that is entirely compatible with the general views of the disabled people's movement, which has long encouraged a community- and home-based focus for health services.

It is not the purpose of this book to denigrate the hospital-based rehabilitation unit. There is now firm evidence for the efficacy of postacute rehabilitation, particularly in the context of stroke. Such units promote recovery and independence and should be a central component of acute healthcare. In addition to the local hospital rehabilitation unit there is a need for a regional specialist rehabilitation centre, which can cater for the needs of those with the most complex and severe physical and psychological problems. Such centres should act not only as centres of clinical excellence but also as centres of education, training and research for the health community as a whole. More such centres are needed but preferably hand in hand with growth in the community services.

We do not propose the redistribution of scarce rehabilitation resources but hope to make a strong case for increasing such resources overall and directing new energies into community rehabilitation. We would like to see all health professionals working more closely in partnership with disabled people and their families, and other social care professionals, within the community and in the home. However, we are aware that new initiatives in the modern health service need to be firmly evidence based and the main purpose of this book is to review such evidence. We hope this will help others make a stronger case for the development of community initiatives. We are conscious that the quality and quantity of rehabilitation research literature in the community is lacking. It is our intention that by reviewing available literature the gaps in the field will become more apparent and the focus of future research become clearer.

We are conscious that this book concentrates on neurological problems and obviously we are aware that many people in the community have a range of other diagnoses, including cardiac, musculoskeletal and psychiatric problems. However, these areas are outside our field of expertise, although we have referred to other groups where particular examples seem pertinent to the neurological field. Throughout this text we have emphasized that it is inappropriate to differentiate between physical disability and the psychological, behavioural and emotional problems associated with disability. It is vital in a community setting to adopt a holistic view of the disabled person, which clearly needs to encompass the whole spectrum of problems that may be encountered.

A note on language. There is a discrepancy within disability groups in the North about the way in which we should refer to disabled people. In disability

groups in America and Canada, and also in professional academic texts in the UK, the preferred term is persons with disabilities. It is based on the people first philosophy – that people come before the disability. However, disability groups in the UK disagree because this implies that the disability is an attribute of the person and not of society. The British social model of disability (see Chapter 3) tends to advocate the use of the term disabled person. We have tried to adopt this approach as far as possible. However, we are aware that the different contexts of the chapters have sometimes required different terminology and we hope not to have caused offence in any chapter by inappropriate use of language. Discussions of semantics should not be to the exclusion of addressing the real issues facing disabled people.

How is the book structured? We have introduced the broad topic of rehabilitation in Chapter 2 with an overview of rehabilitation practice in general and neurological rehabilitation in particular. This chapter introduces the concepts of impairment, disability and handicap as well as the more modern concepts of impairment, activity and participation. In this chapter we review the need for community-based rehabilitation and place this need in the context of the views of disabled people, the developments in the health professions and advances in health systems. We also discuss a number of theoretical models of how community rehabilitation may be delivered in a variety of different settings, from hospital outreach on the one hand to models of independent living on the other.

There has been a tendency in the past for the theoretical constructs of disability to be firmly divided into two camps – the medical model and the social model. These are important concepts for discussion in a textbook of this type and we do so in Chapter 3. However, this chapter also emphasizes the urgent need for more collaboration between the two camps and the need to develop an integrated and dynamic network of partnerships not only between health and social care professionals but also between professionals and the disabled person and their family.

The word community is sometimes used too glibly. The social science literature abounds with various definitions and discussions on the concept of community and these thoughts are put into context in Chapter 4.

The disabled persons' movement now has a long history in many countries, particularly the USA. In that country, and in a few others, it has been instrumental in setting the agenda for rehabilitation services. In many other

countries the views of disabled people are now becoming paramount in designing disability services. This is a trend that should be applauded and encouraged. Chapter 5 attempts to summarize and debate the views of disabled people within a community context.

A particular emphasis of this textbook is on the need to develop a firm evidence base that can act as a platform for the development of future services. We are conscious that many people working in the community sector have little, if any, experience of research and we felt it was appropriate to summarize briefly basic research principles and have done so in Chapter 6. In particular we wish to flag some of the difficulties and challenges of working within the community. However, we hope we have not portrayed these challenges as too severe and put people off the important task of developing a more robust research base for neurological rehabilitation in the community. It was certainly not our intention to do so and indeed we hope we have tried to portray some of the interest and excitement that can be generated by simple research or audit projects and the publication and dissemination of such results.

The key chapter in this book is Chapter 7. In this chapter we have tried to review the evidence base for community rehabilitation. This has been a major challenge. There is sparse high-quality peer-review literature on the subject but nevertheless there is a significant array of small-scale research, both quantitative and qualitative, and a wealth of anecdotal experience. We have tried to summarize an extraordinarily complicated field in a tangible and understandable fashion.

Occasionally health professionals in the North forget that their compatriots in the South have been working in the field of community rehabilitation for many years. In less developed countries there are very few hospital-based rehabilitation facilities and the overwhelming majority of disabled people have never accessed and never will access such a unit. Indeed, most disabled people do not have access to any health professional at all. If there is any contact then it has often been through a Community-Based Rehabilitation (CBR) project, which in turn has often been organized, financed and even run by international nongovernmental organizations (NGOs). Many successful and diverse projects have been established and it seemed appropriate for the North to learn some lessons from the South. Chapter 8 serves this purpose. The CBR literature is diverse and often difficult to access but we have tried to pull together some strands that may be of relevance to this textbook.

Naturally, the book has concentrated on health-related matters but throughout the text we have emphasized the need to consider all aspects of community. Chapter 9 discusses employment rehabilitation as well as issues relating to housing, sport and leisure, transport and driving and education. We briefly touch on issues such as alternative therapies and the role of charitable and voluntary agencies as well as emphasizing the need for support of the carers of disabled people, and indeed support to the family as a whole. We are aware that this chapter has to be somewhat parochial as these broader issues depend so much on the local society, local culture and national legislation. However, we hope that we have portrayed at least some of the evidence that emphasizes the importance of these broader aspects of service provision in the community.

The thrust of the book is towards adults. However, there are significant numbers of children with disabilities who live at home and thus we asked Peter Rosenbaum and Mary Law to provide a chapter, which introduces the concepts of childhood disability (Chapter 10). We are very grateful for their insightful contribution.

Many individuals with neurological disabilities have a complicated range of cognitive, intellectual and behavioural problems, in addition to their physical disabilities. This is particularly true for people with traumatic brain injury and many other diseases, such as multiple sclerosis and stroke. Neuropsychologists have been at the forefront of the management of such problems and many models for neuropsychological rehabilitation have now been developed. This is a specialist field and this book does not attempt to offer a definitive guide to neuropsychological rehabilitation. However, we felt it was important to cover this aspect of community rehabilitation in a little more detail. Thus, we asked Pamela Klonoff and David Lamb to summarize some of the initiatives around the field of neuropsychological rehabilitation in the community. They have provided an excellent chapter (Chapter 11), which reviews this literature and draws upon particular examples of practice from their own unit in Phoenix, Arizona.

### **Illustrative case studies**

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At this point we felt it might be useful to illustrate some of the difficulties that can occur for people with neurological disabilities without appropriate

community rehabilitation and support. Thus, we will briefly annotate four case studies taken from the authors' experience in the northeast of England. For the purpose of illustration these are studies where significant problems have arisen. The studies should not be taken as indicative of the general level of rehabilitation in the northeast! Clearly, many people go through a hospital-based rehabilitation process with an excellent outcome. Sometimes unnecessary problems can arise where there is no community rehabilitation. These case studies will be revisited in Chapter 12. At that point some of the advantages of community rehabilitation will have been illustrated and the literature reviewed. We will then postulate what may have happened if there had been proper community rehabilitation.

### Case study 1

Mr B is a 67-year-old retired gardener. He led an active life and had been fully employed as a railway engine driver until his retirement at the end of 65 years. He has been a moderate smoker and has mild hypertension well controlled with prescription of a diuretic. He had been 2 years into active retirement when he had his stroke. Mr and Mrs B have no children. Mrs B has been mildly disabled with cerebral palsy all her life. She has no cognitive impairments but does have a relatively mild left hemiparesis. She is a little older than Mr B and in recent years her walking has become more difficult for her. She has become much less able to get around outside the house, although she still manages to get around inside the house by holding on to furniture. Mr and Mrs B have no immediate family but live in a small ex-mining community in the north of England and have a number of close friends in their locality.

Mr B had a serious stroke, which left him with a profound left hemiparesis as well as left-sided sensory and visual neglect. He required admission to the local acute hospital where he underwent appropriate investigations, which confirmed a right temporoparietal infarct. He remained on the acute ward and over the course of the next 2 weeks he made slow but steady improvement. At this time he had input from physiotherapy and continued to have medical and nursing support but regrettably there was no active, coordinated rehabilitation and no input from occupational therapy or neuropsychology. After 2 weeks he became depressed and was reluctant to participate in rehabilitation and was becoming anxious about his wife who had been left at home. He was concerned about her ability to cope, although she did have support from her neighbours. He began to stay in bed more and on the busy ward his pressure care was less than satisfactory, and regrettably at the end of the third week he developed a small pressure sore in the sacral area that rapidly progressed over the course of the next fortnight. A further complication arose after about 5 weeks when the pressure sore became infected with methicillin-resistant *Staphylococcus aureus* (MRSA). At this point referral was made

to the rehabilitation centre and he was eventually transferred a further 3 weeks later (now 2 months poststroke). His rehabilitation was hampered by a significant pressure sore, which took a further 3 months to heal. Over this time he had begun to make a reasonable physical recovery from his left hemiparesis and by the time of his discharge, 6 months poststroke, he was able to walk independently and was independent in all self-care tasks. His left-sided visual and sensory neglect had also largely resolved and he was able to return home and continue looking after his wife.

In total he had been in hospital around 6 months. His wife had managed at home over this period of time but only by resorting to an extensive network of neighbour support.

### Case study 2

Mrs W is a 78-year-old lady who is a retired schoolmistress. She lives by herself as her husband died some years previously. She has one son with whom she maintains contact but he lives in London and visits only infrequently. She has no previous medical history and no previous transient ischaemic attacks. However, despite being in good health she had a mild stroke resulting in a right hemiparesis and a degree of dysarthria. Initially her physical disability was relatively mild and she was against going into hospital and thus her general practitioner decided that she be allowed to stay at home. There were, in any case, difficulties in finding her an acute hospital bed.

In the first few days she managed reasonably well and was still just mobile around her home. However, she had difficulty getting to the shops and although she had one or two local friends she was an independent lady who preferred to look after herself and do her own shopping. There was an incline from her house to her local shops and she had great difficulty in getting up this slope. When she did get to the shops she also found communication was awkward because of her dysarthria and she became embarrassed about the slurring of speech.

At some point in the first few days after the stroke she also began to develop troublesome spasticity and after the first week or so her gait became worse and she was less able, and less willing, to go out of the house by herself. A few weeks after the stroke her gait had slowed further, secondary to the spasticity, and she became occasionally incontinent. The incontinence was probably due to her slowed gait and her difficulty getting to and from the toilet rather than any inherent bladder difficulty. Her general practitioner remained intermittently in touch with her but she had no other rehabilitation support. She became more and more isolated in the home and more dependent on her neighbours. Probably as a result of all these difficulties she became depressed, which in turn further worsened her mobility and her interaction with her friends.

Eventually, around 3 months after the stroke, her general practitioner decided, with her reluctant agreement, that she was no longer able to live at home and she was admitted to a local nursing home.

### Case study 3

Mrs M is a 33-year-old lady who has had multiple sclerosis for the last 8 years. Initially she had two relapses over the first 2 years of the illness and then entered a reasonably static phase. Over this time she had a relatively mild spastic paraparesis and a relatively minor degree of urinary frequency and urgency. However, in the previous 2 years she had three further relapses and on each occasion the relapse further weakened her legs and her bladder symptoms. In addition she developed a relatively minor degree of ataxia of the hands and a slight degree of dysarthria. However, in between the relapses she largely reverted to her previous physical state although there was probably a minor overall worsening of the symptoms. She lives at home with her two daughters aged 10 years and 8 years. She is married but her husband works on the oilrigs in the North Sea and is away from home for several weeks at a time. Her parents have died but she has a sister who lives nearby who has her own family, and although she is able to help out her involvement needs to be minimal. Mrs M worked as a receptionist for a local small business.

At each of the relapses in the last 2 years she had been admitted to the local neurology department for administration of intravenous steroids and physiotherapy but nevertheless the admissions caused her considerable inconvenience as her children then needed to be looked after by her sister and Mrs M needed several days off work. Her employer dismissed her after her most recent relapse. Mrs M is currently taking this employer to an industrial tribunal for unfair dismissal but at the moment remains out of work.

### Case study 4

Mr Y is a 23-year-old man who at the time of his accident was living at home with his parents. He was unemployed. He was the driver of a car that was involved in a collision with a lamp-post and as a result of the impact Mr Y had a severe traumatic brain injury. He had a few minutes of retrograde amnesia and around 3 days of posttraumatic amnesia (PTA). He was admitted from the scene of the accident to the neurosurgical department but did not require any neurosurgical intervention. He was monitored over the course of 10 days or so as he emerged from coma and PTA and about 2 weeks after his accident was transferred to the local regional head-injury rehabilitation centre. At that stage it was clear that he had made quite a good physical recovery from his injuries and was only left with a mild left hemiparesis, which was of very little functional significance.

The situation, however, was complicated by his severe behavioural problems. He became easily physically and verbally aggressive to the staff. The situation was compounded by difficulties with recent memory, poor concentration, impaired information-processing speed and consequent difficulties of both learning about and cooperating with a rehabilitation programme designed to assist his behavioural problems. He needed constant

prompting, guidance and supervision. The neuropsychologist at the centre, with the support of the nursing and therapy staff, put together an active behavioural rehabilitation regime. However, Mr Y consistently failed to cooperate with the programme. His parents were also rather antagonistic to the programme and wished him to be discharged home. Considerable effort was expended in trying to assist Mr Y with the behavioural regime. Further efforts were made to explain the nature of his problems to his parents. However, little progress was possible and after about four weeks on the brain injury unit Mr Y took his own discharge against medical advice, with the assistance and cooperation of his parents. However, his problems, not surprisingly, continued while he was at home. The home situation was fraught and his parents were finding it increasingly difficult to cope with his behavioural problems. After about a further month they decided they could not cope any more and Mr Y moved into his girlfriend's house. She already had a young child and the situation became even more fraught as Mr Y was verbally aggressive, but fortunately not physically aggressive, towards both his girlfriend and the small baby. Eventually this situation broke down and Mr Y moved into a local hostel for homeless men. At this point he began to drift into crime and was eventually arrested for taking a vehicle without the owner's consent. Mitigating circumstances of his head injury were pleaded by some of the staff from the regional head-injury centre and Mr Y did not receive a custodial sentence. After this he decided to move out of the area and moved to London to live with his brother. No further details are available.

Readers are invited to bear these case studies in mind throughout the book. We make some suggestions for how these situations could have been avoided in Chapter 12 but the reader will no doubt develop alternative ideas about how these unfortunate scenarios could have been prevented by appropriate community rehabilitation.

In summary, we hope this book addresses the need to develop rehabilitation services within the community and summarizes the current evidence base for the efficacy of such services. This case is not made in an attempt to pull resources away from the hospital rehabilitation unit but is made as a case to increase resources, services and facilities into the field of rehabilitation as a whole. We firmly believe that community rehabilitation is part of an integrated and dynamic network of services. The artificial boundaries between health and social care are blurred and should become more blurred so that the focal point for resources becomes the disabled person.